Incidence and instability of explicit requests for euthanasia in a palliative care hospital

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A concise and informative title:
Proposition: Euthanasia requests in a palliative care hospital
Abstract

Background:
In the current public debate in France about end-of-life and legalization of euthanasia, palliative care is considered variously as a suitable answer, an alternative or even a supplement to euthanasia. This debate is based on opinion surveys, partly because there is a lack of objective data about the incidence of euthanasia requests (ER) in palliative care settings. The aim of this study was to provide such data, based on computerized records for patients admitted to an 81-bed palliative care hospital (PCH) in Paris.

Methods:
Were searched for the word “euthanasia” and all the expressions relating to death in the computerized medical and nursing notes of patients in the PCH in 2010-2011. Each verbatim record was classified into one of three categories: euthanasia (including ERs), wish to die (WD) (without ER) and considering palliative care as a euthanasia-like practice. Repeated ERs were analyzed according to a grid for a qualitative analysis.

Results:
We found that 61 of the 2157 patients in the PCH (3%) formulated an ER, 17 (1%) described thoughts of suicide (ST) and 146 (7%) expressed a wish to die (WD). Overall, 44% of the patients formulating an ER also expressed a WD at another time, without an ER. These patients stayed longer in the unit than the other patients (median 24 vs. 13 days), and consumed more anxiolytics and antidepressants. None of age, disease or marital status was associated with ER. More women
and widows than men and married women expressed a WD. Six patients (0.3%) repeated their ER: all had poorly controlled symptoms with repercussions for their mental state.

**Conclusion**

Our data confirm the low incidence of ER in a PCH. The observation of ER in the PCH is suggestive of good communication between the patients and the care teams. These ERs are unstable and many become a WD or even stop; nevertheless, this should not call the veracity of these requests into question, but rather lead to a consideration of the dynamic changes in these requests, and to care staff paying additional attention to the person, their suffering and the context.

**Keywords**: palliative care, palliative care unit, euthanasia, requests,
Background

The possible legalization of euthanasia is currently a question provoking substantial public debate in several countries. In France, the law of April 22\textsuperscript{nd} 2005 concerning the rights of patients at the end of life (the so-called “Léonetti law”) permits the limitation or stopping of treatment, differentiating these situations from euthanasia, which remains prohibited [1]. Public debate is affected by ideological position-taking and political issues, and is essentially fed by emotional reactions to highly publicized individual situations and opinion polls; for example, a poll in October 2012 indicated that 86% of the French population was in favor of the legalization of euthanasia [2]. This high proportion contrasts with the impression that caregivers have of rarely being confronted by such euthanasia requests (ER). The first scientific data concerning conditions at the end of life in France have just been published [3, 4]. By contrast, data of this type have been published periodically for almost 20 years in neighboring countries, such as Belgium and the Netherlands, which have since legalized euthanasia if certain circumstances are met [5–10].

A survey of French doctors reported that 1.8% of patients had explicitly requested euthanasia [3]. Although difficult to evaluate, the unbearable nature of suffering at the end of life is one of the principal reasons for such requests, and is indeed an essential criterion for a positive response to such requests in the countries in which this practice has been legalized [11, 12]. Favoring the development of palliative care is often put forward as an alternative in debates on possible changes to laws concerning the end of life, with the risk of reinforcing opposition between palliative care organizations and advocates of euthanasia [13–15]. Despite the development of palliative care in France, most of those calling for the decriminalization of euthanasia or physician-assisted suicide do so in response to intolerable situations they have seen afflicting their relatives or friends at the end of life (report of the French National Ethics Advisory Committee, the CCNE) [14]. Indeed, the impact of palliative care on ER and the stability of such requests remains unclear and in France this...
issue is still the subject of debate [15–17]. Palliative care units manage patients including those in the most complex situations, and have to deal with ER. But, as pointed out by the CCNE report, it would be unrealistic to think that palliative care can deal with all the possible situations of suffering at the end of life and that such care would eliminate all requests to die [14].

In an attempt to provide some objective data to enrich the public debate about euthanasia, and to which palliative care is extremely pertinent, we evaluated the incidence of different formulations of wishes to die within the population of patients in a palliative care hospital (PCH). A “wish to die” may be expressed in several ways. Between the wish to not prolong life artificially and an ER, there is a whole range of expressions: the desire not to prolong life, the wish to die “quickly”, the wish to hasten death, the wish to end life and others; the differences in expression and meaning can be subtle such that it may be difficult to distinguish between them, and lead to confusion for care staff and relatives. The original aim of our work was to distinguish clearly between ER or thoughts of suicide (ST) and other wishes to die (WD) and to observe how they change over time.

Maison Médicale Jeanne Garnier is a hospital totally dedicated to palliative care, and is recognized for its high level of competence and expertise in end-of-life care. It has 81 beds in six palliative care units (PCU) and admits more than 1100 patients annually. Most (96%) of the patients are in the terminal phase of cancers, with most of the others suffering from progressive neurological diseases. The death rate is 87%, with no significant difference between the six units.
Methods

In three steps:

- Extraction of relevant information from verbatim medical observations and care notes
- Analysis of context of the extracted verbatim notes by two researchers
- Classification of each verbatim note into one, and only one, of three groups: ER (euthanasia request), ST (suicidal thought), WD (wish to die) – or exclusion.

Targeted descriptive analysis of inpatient records in cases where the ER was reiterated.

Definition of the notion of euthanasia and the wish to die

A multidisciplinary working group of doctors, a psychologist and nurses defined the vocabulary before the start of the study. The following definition of euthanasia was adopted: an act deliberately designed to end the life of a person suffering from a serious incurable disease, at the request of that person, to put an end to a situation that the person considers unbearable [14]. This definition excludes requests made to care staff by members of the patient’s family.

The ER group was differentiated from a WD group, where WD is defined as the expression by the person concerned of a wish to die or to be dead, but without explicitly requesting the assistance of a third party. A wish for the end of life to be short, for time to pass rapidly, or to die quickly was classified as WD if the patient did not explicitly request an act to accelerate death. Suicidal thoughts (ST group) were classified separately.

Data extraction and analysis

All the medical and paramedical records for patients at the PCH are computerized (Osiris software, Corwin). The sociodemographic data for all the patients hospitalized in 2010 and 2011 were
collected. We then integrated the pathology data, data concerning the characteristics of the stay in the PCH (dates of admission and discharge, duration) and the anxiolytic and antidepressant treatments administered during stays in the PCH (SAP Business Objects Web Intelligence software). We defined an instance of a carer or doctor writing a free text entry in the computerized file as an observation or transmission. The working group chose to conduct a wide-ranging search, to ensure that the identification of ER and of expressions of WD was as exhaustive as possible. Table 1 indicates the computerized searches carried out on all the verbatim medical observations and notes written by paramedical staff (nurses, care assistants, psychomotor therapists and physiotherapists), psychologists and art therapists.

The extracted verbatim notes were reread and analyzed in context by two researchers, in a non-random chronological order. The notes provided by social workers were excluded because they often included the word “leave” (partir), which (in French) is ambiguous and was mostly used to refer to a return home or transfer to another care structure rather than death.

Each verbatim note was classified into one, and only one, of three groups: ER, ST or WD. If the verbatim note could not be classified into one of these groups, it was classified as “other”. All references to a previous ER, conversations with staff about euthanasia, requests from relatives and indications that palliative care was perceived as a type of euthanasia were identified, counted and, not being true ER, excluded. The classification of each verbatim observation into one, and only one, group allowed a hierarchy of items to be established, with explicit ER at the top, followed by ST. If there were several verbatim observations for the same patient, these patients could belong to several groups. For this reason we will describe the relationships between groups.

*Study of repeated requests*

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We analyzed the files of all the patients who had formulated an ER and checked for the following elements in all cases of repeated ER during the hospitalization: previous ER in the preadmission file, date and duration of the request during the stay in the PCH, and the person to whom the request was made. The working group established a grid for the qualitative analysis of these files, including the following elements:

- The temporal nature of the request (its duration),
- Disease, symptoms and psychological or spiritual suffering,
- Pharmacological and non-pharmacological treatments,
- The offer and use of sedation,
- Multidisciplinary clinical management of the patients,
- Interactions with the family.

**Statistical analysis**

The descriptive statistics are expressed as frequencies and percentages for categorical variables and as means and standard deviations (SD) for age at admission. Durations of stay in the unit are expressed as medians and interquartile ranges (IQR). We used chi² tests, Student’s t tests and Mann-Whitney U tests to compare groups, as appropriate for the type of variable. Univariate analyses were carried out to estimate the relative risk (RR) with a 95% confidence interval for belonging to a particular group. The significance threshold was fixed at \( p=0.05 \) for two-tailed tests.
Results

Delimitation of the sample

In 2010 and 2011, 2157 patients were admitted to the PCH, in which they stayed for a median of 13 days (IQR: 6 to 26 days; tables 2 and 3). The analysis included 33024 medical observations and 195 862 nursing notes, corresponding to a mean of 0.7 medical observations and 4.3 paramedical notes per patient per day (table 2). The computer search (table 1) extracted 2080 relevant observations or notes, corresponding to 917 patients.

Classification by group (table 2)

As indicated in table 2, 335 verbatim notes corresponding to 195 patients were attributed to the three groups. The ages, marital status and diseases did not differ between these other patients in the PCH (table 3). However, more of these patients were female (p<0.01), the median duration of stay in the unit was significantly longer, and they were more likely than other patients to be treated with anxiolytics (RR=3.7; 95% CI: 2.4 – 5.6) and antidepressants (RR=2.2; 95% CI: 1.7 – 2.8).

There were 100 verbatim observations including an explicit ER (ER group) formulated by 61 patients. These 61 stayed longer in the unit and were more likely than other patients to be treated with anxiolytics (RR=7.4; 95% CI: 2.7 – 20.4) and antidepressants (RR = 2.6; 95% CI: 1.6 – 4.2). The sex, age, family status and diseases of these patients did not differ from those of other patients. The first request was made to a doctor (51% of cases), a nurse (39% of cases), a psychologist (7% of cases) or a care assistant (3%). This first request was made a median of six days after admission to the hospital (IQR: 2-14). The median interval between the last request and the end of the patient’s stay was seven days (IQR: 3-16 days).
Seventeen patients expressed the idea of suicide (ST group), with no significant difference between this group and other patients for age, marital status, disease or sex despite most being men; however, they were more likely to be given antidepressants (RR=5.8; 95% CI: 1.9 – 17.7).

The WD group included the 147 patients who expressed a desire to die: he or she spoke about this desire, wish or determination to die, to “leave” or to pass away, but without requesting the assistance of a third party to accelerate the process. Most of this group was female ($p<0.0001$; RR: 2.1 (95% CI: 1.5 - 3) and many were widows.

The “other” category included 1745 verbatim observations/notes (84%) that, after rereading and contextual analysis, could not be classified into any of the three initially defined groups. Table 2 indicates the frequencies of particular verbatim relevant to euthanasia: discussions about a previous ER or about euthanasia without an explicit request, a request from a relative (not confirmed by the patient), and evidence of the view that palliative care is a type of euthanasia or associated with an euthanasia-like practice.

**Relationships between groups**

We found that 43% ($n=26$) of the ER group had also at some time expressed a WD (Figure 1A). Of the patients expressing a WD, 18% formulated, at some time, an ER. Few ER patients ($n=2$) expressed a wish to kill themselves (ST group).

**Repeated requests for euthanasia**
Six of 61 patients reiterated their ER; this corresponds to 0.3% of the total population and 10% of the patients formulating an ER (table 3). The characteristics of these patients are summarized in table 4: four of the six patients were over 83 years old, such that the mean age of this group was nine years older than that of the ER group. All had poorly controlled symptoms, with repercussions for their mental state. For the four oldest patients, the duration of the requests for euthanasia covered between 30 and 100% of their stay in the PCH, with a corresponding number of repeated demands. For the two younger patients (49 and 69 years), the request was repeated only three times over three days. In half these cases, the notion of an ER was recorded in the patient’s preadmission notes.

*Trajectories of the patients repeating the ER (table 4)*

Patient 1

On admission, the patient expressed an ER, repeated over three days, subsequently moving towards an expression of the WD. During her long period of hospitalization (62 days) she received reinforced multidisciplinary care and effective antidepressant treatment. Her sadness attenuated and one week before her death she complained that she was sleeping too much.

Patient 2

During the first 15 days in the PCH, this patient’s symptoms worsened, with the occurrence of an episode of respiratory distress and an increase in pain: debilitating mycosis, sensations of hunger and thirst, and anguish. Evidence of exhaustion emerged in association with respiratory degradation. The patient became fearful of suffocation, leading to a state of panic. The patient asked very clearly “to die by an injection now”. His demand persisted for three days and then shifted, in the context of the PCH and his wife’s incomprehension, towards a request for continuous sedation until his death.
Patient 3
A combination of three elements were behind this patient’s request for euthanasia nine days after his admission to the unit: a decompensated painful symptom that it was impossible to relieve in a satisfactory manner; a conflict with his daughter that worsened his anger and discomfort; and his determination to not let himself down and to retain his autonomy in decision-making right to the end. The request was repeated over a period of two weeks until, in the last week of his life, under the influence of an increase in sedative treatments, he became increasingly sleepy, and ceased requesting euthanasia.

Patient 4
This 84-year-old patient had been a classical dancer and he found the change in his bodily integrity and major damage to his body image intolerable. From his admission to the unit, he requested euthanasia, and he continued to repeat this request, showing photographs of himself in his stage costumes, until his death seven days later.

Patient 5
The first reference to an ER came from the son of this patient, on her admission. The patient herself expressed her wish to die in several different ways. Filled with an intense existential suffering, she requested euthanasia two days after her admission. She repeated this request four times over a period of eight days, but the request was always tinged with ambivalence, as the patient displayed curiosity and pleasure at being alive on a number of occasions. During the five days before her death, her physical weakening and a concomitant decrease in consciousness due to anxiolytic treatment lead to a cessation of her requests.

Patient 6
The son of this patient transmitted her wish for euthanasia at the time of her admission. For the first week, she was not in pain and suffered little dyspnea. However, the patient’s dyspnea and anxiety then worsened and she began to ask for euthanasia. She formulated a request for euthanasia after 10 days, which she repeated over a period of three weeks until about two weeks before her death. At the same time, she said that she enjoyed spending time with her children. When she received a positive response to her demand to be transferred to Belgium to have access to euthanasia (this patient was originally from Belgium), her demands ceased and the question of euthanasia was never brought up again: the patient’s symptoms disappeared, and she became comfortable again.
Discussion

Frequency of ER and WD in the PCH

Our study documents the occurrence of requests for euthanasia at the end of life in a palliative care setting. It confirms the findings of Ferrand who reported requests for hastened death made to French palliative care teams [15]. The low frequency of such requests, 3% of the patients hospitalized in the PCH, is nevertheless higher than the 1.6% reported in 1999 in a French study of 611 patients hospitalized in five PCUs [16]. More recent figures reported by a mobile palliative care team (1500 patients over a period of five years) are closer to ours, with 4.3% of patients requesting euthanasia and 0.6% of patients doing so in a persistent manner [17]; however, this previous study also included requests formulated by relatives. According to a Dutch survey in 2010, there was an explicit request for euthanasia before 6.7% of all deaths, compared to 4.8% in 2005; this report provided no information about palliative care [9, 18]. A survey of general practitioners in Belgium noted that 27 of 200 non sudden home death patients (13.5%) had at some time formulated an ER; the authors reported that these wishes varied widely between patients, in both their formulation and timing [19]. Other studies are difficult to analyze, as they do not differentiate between ER and WD [20–22].

We found that 7% of terminally ill patients in our PCH spontaneously expressed a WD, consistent with the frequency reported in a Greek palliative care unit [23]. The value was higher (14 to 17%) when a self-report measure was used to ask all terminally ill patients systematically about their desire for hastened death [20, 24]. These high frequencies contrast with the low frequency of strong WD (2%) reported in a sample of ambulatory cancer patients: therefore, the closeness to death and survival time may make very large contributions to such requests/desires [22]. A WD was clearly associated with depression and hopelessness [20, 24–26]; we found also that antidepressant and anxiolytic consumption by these patients was higher than by other patients. Possibly, this is because
the greater needs of these patients are recognized leading to more extensive use of pharmacological solutions.

To our knowledge, the predominance of female patients among those expressing a WD has not been reported before; no such predominance is found for ER. Women hospitalized in PCH are more likely to report a lower quality of life [27, 28], and women experience more overall psychological or existential distress than men [29]. This apparent difference between the sexes about WD needs to be confirmed and analyzed, possibly by using a qualitative approach to compare the statements of male and female patients.

Requests for euthanasia and palliative care

For more than 20 years, it was generally considered that ER was less likely in palliative care than in other contexts [30–32]; however, this opinion is currently the subject of debate, especially in all countries where euthanasia is legalized [6, 33–35]. In Belgium, euthanasia in response to explicit requests is more frequent in palliative care units than in other types of care settings [10]. According to Belgian law, palliative care must be provided before euthanasia. One of the characteristics of the practice of palliative care is that there is no unnecessary prolongation of life and that the wishes of the patients are respected, particularly as concerns decisions to stop or limit treatments with no objective other than the prolongation of life [32, 36, 37]. Nevertheless, we show here that there were ER in our PCH. This reflect the good communication between the patients and the care teams; and the provision of palliative care might help patients express ER [10]. We found that it takes time (median of 6 days) for this request to emerge and that the patients formulating ER are those staying longer in the PCH. However, according to the EAPC, the situations in which euthanasia or assisted suicide are requested are often complex and therefore require the expertise of a palliative care team, to listen to, understand and support these patients [32]. Consequently, making an ER is one of the
reason for admission into our PCH. However, the lag before the emergence of demand might reflect
the time required to establish a climate of confidence between the patient and the team in a
multidisciplinary environment, and, indeed, doctors and nurses are approached in 90% of the first
requests. This observation raises the issue of the influence of the attitudes of doctors about
euthanasia: Kelly showed that demands were more frequent when doctors were in favor of
euthanasia [38]. Interestingly, it has been pointed out that the opinion of palliative care and related
organizations has, during the last 20 years, moved from opposition to a “studied neutrality” [39].
Note also that the observation of ER may depend on the attentiveness and quality of listening of the
caregiver rather than his or her personal convictions or the policy or position of the institution.

Persistence of inpatients’ requests for euthanasia

We found that the ERs were transitory, and only 10% of the ER persist throughout the
hospitalization. Some published studies report that a desire for death or a will to live is highly
unstable even over brief periods among cancer patients, especially when they enter the terminal
stage [40–43]. According to Ferrand, 34% of requests persist, but the duration of this persistence
was not specified. This figure highlights the importance of considering the impact of management
on the instability of the request.

We followed the trajectories of the six patients whose requests for euthanasia were persistent. In
four of these patients, decompensation of symptoms (pain, dyspnea, anxiety and depression) was
initially of prime importance. These results are consistent with published findings [20, 26, 43, 44].
However, despite the control of symptoms and multidisciplinary management, ERs may persist,
probably due to other more complex factors; such factors may reflect the expression of a desire to
remain autonomous to the end or the loss of ability to tolerate physical psychological, social or
existential suffering such as a loss of self-esteem [12, 22, 43, 45, 46]. In some cases, the ER only
ceases when the patient’s clinical state deteriorates or the patient experiences a decrease in
consciousness, possibly a consequence of sedative treatment. In such cases, the change in the patient’s condition prevents him or her from reformulating an ER.

**Request for a hastened death: between a wish to die and a request for euthanasia**

Our data show the variety of ways the wish not to live longer can be expressed, from an explicit request for euthanasia and a wish to die without the intervention of a third party. Clarification of the difference between an ER and the wish to die makes it possible to understand the interaction between the two. About two in five patients formulating an explicit ER also express a WD without the intervention of a third party. One in five of the patients expressing a WD makes an explicit request for euthanasia. This suggests that ER and WD are in the same subjective register with respect to life: the patient no longer wishes to live. However, the desired mode of death is unclear. The observed instability of ER should not call into question the veracity of these requests, but should lead to consideration of the dynamic changes in these requests, and to care staff paying additional attention to the individual, his or her suffering and the context. Work involving interviews of cancer patients with short life expectancy indicates that wishes for euthanasia or physician-assisted suicide are different from ER: wishes remain hypothetical and are fluctuating and ambivalent [42].

In France, unlike Switzerland, there has not yet been any significant media communication or debate about assisted suicide. This may explain the small number of patients, more male patients than female, requesting assisted suicide. We found that the patients requesting euthanasia differed from those raising the possibility of suicide, with almost no overlap between these two groups. This may be linked to differences in patient expectations: euthanasia could be perceived as a “therapeutic act” in the medical field, whereas assisted suicide could be more personal, with a lesser role played by care staff.

**Limitations of this study**
Our study is based on the verbatim notes in which the care staff retranscribed what they had heard, leaving a certain margin for error between what the patient actually said and its interpretation and retranscription by the career. These possible effects of interpretation and of the transcription or lack of transcription of requests raise issues about the exhaustiveness of the data. It is routine practice in PCH to retranscribe everything reflecting or describing the complexity of the situation, but care staff confronted with such requests may also wish to distance themselves from them, making it difficult for them to transmit this information. For this reason, only a prospective quantitative and qualitative study would provide both exhaustive data and a more rigorous understanding of the relationship the care staff of the PCU have to the expression of a request to hasten death from a patient.

Our study was conducted in a single hospital. Nevertheless, the hospital includes six palliative care units, such that the findings may be representative of palliative care in the Parisian region more generally.

**Conclusion**

There are ERs in PCH, but they are not prevalent (3% of patients) and are transient: only 10% of these requests were repeated. Their existence in the context of palliative care indicates something of a paradox: the PCH provides an environment attentive to the patient, allowing such requests to emerge; however, it is also an environment intended to ensure that patient care and support are such that demands of this type are unnecessary. However, the reality is that palliative care teams are confronted by ERs, and this may become more frequent because of possible changes to the law. Our preliminary observations require confirmation in a prospective quantitative and qualitative study taking into account the dynamics of interactions between patients, relatives and care staff.
List of abbreviations

CCNE: comité consultative national d’éthique (French National Ethics Advisory Committee)
ER: euthanasia request
PCH: palliative care hospital
PCU: palliative care unit
ST: suicidal thought
WD: wish of to dye

Competing interest

We declare that we have no competing interests

Authors' contributions

Frédéric Guirimand participated in the conception and design of the study, supervised the data collection, coordinated the study, performed the statistical analyses and drafted the manuscript.

Etienne Dubois made the data collection, analyzed the files of all the patients who had formulated an euthanasia request and participated in the analyse

Lucy Laporte extracted verbatim notes (data collection) and performed the statistical analysis

Jean-François Richard participated in the conception of the study and critically revised the manuscript

Daniel Leboul participated in the conception of the study, supervised the data collection and analyzed the files of all the patients who had formulated an euthanasia request and draft the manuscript

All authors read and approved the final manuscript
References


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Figure 1A: Overlap between groups ER “Request for Euthanasia” and WD “expression of a Wish to Die”. There are 26 patients common to the two groups, reflecting fluctuation between WD and ER during the stay in the PCH.

Figure 1B: Overlap between group ER with group “Thoughts of Suicide” (ST). Only two patients were common to these two groups, reflecting the distinction between these two formulations of a desire for death.

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Additional files provided with this submission:

Additional file 1: guirimand Table 1.docx, 15K
http://www.biomedcentral.com/imedia/1905349843129622/supp1.docx
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